



FARE

Food Allergy Research & Education



*Parents have many dreams for their children ...
Mine was that my son, Timmy, just stay safe.*

Managing Timmy's food allergies was a full-time job. Every meal, snack and activity needed to be planned for him. Like many of you, I ate Timmy's diet whether I was with him or not because if I kissed him, or even came too close in a hug, he could have a reaction.

It took a village to keep him safe – a team of doctors, nutritionists, CPR and epinephrine-trained caregivers and teachers, specialized food manufacturers, a very understanding sister, a supportive husband and family, great friends and me focusing on Timmy's food 24/7.

Like children facing other severe illnesses, children with food allergies are forgoing the simple thing that most children take for granted- a carefree childhood. Food should be something that is life-sustaining, not fear-inducing.

We train our children and they watch us read ingredient labels, ask if a food is safe, train everyone in the use of epinephrine auto-injectors and when they should be used. They "get it" – that they could die – even if we don't talk about it to them. I know because my son Timmy, even at the age of four, understood all too clearly what eating the wrong food could do to him.

Anaphylaxis. It is a medical term that barely does justice of explaining what it feels like to be on the verge of death. One's airway is closing. Blood pressure dropping. Absolute internal panic. With only one remedy that only *might* work with immediate administration – epinephrine.

In December 2011, Timmy needed emergency epinephrine as his throat started to close after the tiniest drop of a supposedly safe food passed his lips. He received an epinephrine injection within seconds and it thankfully worked. He was fine and I was absolutely shattered.

We decided to see if Timmy might qualify for a Phase I multi-food/Xolair® clinical trial at Stanford University. We felt strongly that we needed to help researchers propel their important work forward. We hoped something they learned might help Timmy and the millions of children like him.

Timmy's evaluation, as with many other clinical research trials, required standard skin tests, blood tests, additional screenings, and Double Blind Placebo Controlled Food Challenges (DBPCFCs). In DBPCFCs, the patient eats the food allergen hidden in a safe food in small increasing amounts over a period of time without knowing which food allergen is hidden, if at all. It can be emotionally challenging, but is extremely informative to both the researchers and the patient. One often learns a great deal about how one's child may react to each different allergen – not just the amount. Some kids immediately vomit. Some say their lips itch; others get hives or flushing. Some consume next to nothing of the allergen, yet symptoms begin. Timmy reacted to an amount equivalent to a grain of sand. Others can consume a lot more before a symptom begins.

When Timmy reacted, I have to say that I felt vindicated (as well as absolutely terrified). I was not some hysterical mother making his allergies a big deal for nothing. His allergies were serious and we had thankfully been doing everything right to keep him safe. We were so grateful for the advice and support we had received over the years.

We learned that he qualified for the trial and in February 2012, we committed to follow the protocol for at least the next 18 months and to consider participating in any follow-up studies. He began his treatment of Xolair® – a shot in each arm every few weeks for several months.

And then the real work began. The strictly regimented protocol called for Timmy to eat his allergens, slowly increasing his dose over time. The regimen was stressful for all of us- just looking at an allergen was challenging – asking Timmy to eat it was terrifying and then getting him to eat "poison" impossible... Yes, he called it poison. I had never used that word but that is how he viewed it – and you know what? So did I.

So from April through July of 2012, he took his dose every day – graduating with an every day maintenance dose of 8 grams of egg protein, equivalent to a large egg, and 8 grams of milk protein, equal to a big tall glass of milk.

We have kept it up for over two years and we will continue to do so until we are told otherwise. We are vigilant and keep track of what he eats, how much and when. We always have his emergency medicine with us. We follow his protocol and we attend all of his check-ups.

Is he still allergic? I don't know. He would need to stop consuming his maintenance dose and avoid the allergens for a long period of time before doing another set of DBPCFCs to find out. One day, we might do that. For now, he is desensitized and, more importantly, enjoying a carefree childhood.

He eats in restaurants, enjoys pizza and cake at birthday parties and playdates. He eats lunch in the cafeteria sitting next to classmates drinking and eating foods that could have previously set off a tragic reaction. And he continues to consume milk and egg without issue, but it was never about the food.

I never dared to dream that he could someday eat eggs or milk. But we were hopeful that a safer life for him was possible – a life without fear. We had hoped he could just co-exist safely in a world that contained them. Research changed the course of his life.

We want every child with food allergies to live a safer life and that means that we need to support research- volunteering with our time, financially supporting FARE so research can continue, and by participating when possible.

So many people – researchers, doctors, nurses, volunteers, and donors came together to help Timmy find more freedom by giving him more safety.

Participating in a clinical trial is not easy. It is extraordinarily challenging – psychologically and physically!

Clinical trials are commitments. They are agreements between all of us to do what we can to overcome food allergies – to keep our children safe. Over the years, as I have watched other children participate, I have seen them become empowered. I saw the same with Timmy as well as my daughter who is his greatest cheerleader.

At your next appointment with your allergist, please ask about participating in a clinical trial, if there is one taking place near you.

The researchers, together with FARE, have managed the impossible – identifying multiple paths that may lead to improved treatments and hopefully a cure. I feel confident in saying that we can see the finish line, but we need everyone's help to reach it.

Amie Rappoport McKenna served as the first Executive Director of the Food Allergy Initiative (FAI) from 2000-2005. Among her many achievements is helping to draft and secure the passage of the landmark Food Allergen Labeling & Consumer Protection Act (FALCPA). She joined FAI's board of directors in 2007. Today, she serves on the board of directors of Food Allergy Research & Education (FARE), which was created in 2012 by the merger of FAI and the Food Allergy & Anaphylaxis Network (FAAN).

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